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**Short literature notices: Review of MacKellar, C. and Betchel, C.: 2014,
The Ethics of the New Eugenics**

Roduit, Johann A R

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Short literature notices

Roberto Andorno

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Cooper, M. and Waldby, C.: 2014, *Clinical Labor: Tissue Donors and Research Subjects in the Global Bioeconomy*. Durham, NC: Duke University Press. 296 pages. ISBN: 978-0-8223-5622-6. Price: \$24.95.

Bioethicists, clinicians and regulators tend to conceptualise donation of gametes and reproductive tissue and participation in clinical research as altruistic acts, performed in order to help infertile couples or future patients. In *Clinical Labor: Tissue Donors and Research Subjects in the Global Bioeconomy*, Melinda Cooper and Catherine Waldby challenge this conceptualisation by instead analysing these activities as work—as an informal *clinical labour* that is essential to value creation in the global bioeconomy and often performed to make money (or, in late phase clinical trials, to have access to otherwise unavailable healthcare).

The first chapter presents the book's theoretical framework, a "clinical labour theory of value", distinguishing it from its Marxist forerunner by its emphasis on the embodied and experimental nature of value creation. The second chapter describes the broader historical context in which clinical labour emerges, highlighting increasing labour outsourcing and the shifting of risks from firms to workers, as well as the blurring boundaries between workplace and household. The following three chapters focus on reproductive labour, the harnessing of human (especially female) reproductive biology for commercial and innovative ends. The authors first examine gamete vending and commercial gestational surrogacy in the US,

before turning to the transnational European oocyte and Indian surrogacy markets, and finally to the use of reproductive tissue in the stem cell industries. The last three chapters explore the experimental labour of research subjects enrolled in the global clinical trial enterprise. Cooper and Waldby detail how this labour, once typically performed by prison inmates and academic hospital patients in the US, is now increasingly outsourced to the burgeoning Chinese and Indian economies.

The account of the internal mechanics of these informal labour markets is combined with careful analysis of their complex socioeconomic, political and legal preconditions. In particular, the authors demonstrate their dependence on populations whose vulnerability—economic (unemployment or job insecurity) or physical (lack of health insurance)—make them willing to assume bodily risks in exchange for money or healthcare. They identify the trends towards economic liberalisation and deindustrialisation that underlie the emergence of these populations and the international regulations that permit their enrolment in the global bioeconomy.

One virtue of *Clinical Labor* is that it reveals the brute commercial nature of some of the bodily exchanges on which biomedical innovation increasingly relies. It thus helps dispel the air of altruism and voluntariness that surrounds these exchanges and that arguably impedes an accurate ethical appreciation of them. Equally valuable is its exposure of the precarious living conditions from which clinical labour arises. The book raises important questions for scholars working at the intersection of bioethics and political philosophy, especially concerning responsibility for social injustice. Therefore, even though Cooper and Waldby are critical of bioethics, regarding it as facilitating the creation of clinical labour markets by promoting informed consent and contractual relations between clinicians and tissue providers

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or research subjects, their book can be expected to significantly advance bioethical debate.

One may worry that the authors stretch their analysis too far when they classify umbilical cord blood and foetal tissue donation and patients' reporting of drug consumption habits on social networking sites as "clinical labour". Like the other practices they examine, these too undeniably allow deriving scientific and commercial value from (often burdensome) biological processes. But they are unremunerated, in money or in kind, and therefore unlikely to disproportionately enrol the underprivileged. Nor do they expose the provider to risks other than those already assumed. Hence, unlike other clinical labour, they lack the character of hazardous work chosen because of economic or medical need. This mild complaint notwithstanding, *Clinical Labor* is highly recommended reading.

Erik Malmqvist
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MacKellar, C. and Betchel, C.: 2014, *The Ethics of the New Eugenics*. Oxford: Berghahn. 242 pages. ISBN: 978-1782381204. Price: £60.00

The Ethics of the New Eugenics, commissioned by the Scottish Council on Human Bioethics and authored by Calum MacKellar and Christopher Betchel, is an ethical evaluation of new eugenic procedures and their legal implications. The book seeks to introduce, examine, and analyse the new eugenics while stimulating public discussion about it (pp. 28–29). It addresses "the perceived resurgence of eugenics in the increasingly common procedures available in assisted reproductive technology" (p. 290). After clarifying key terms such as health, enhancement, normality, therapy, and different meanings of eugenics, the authors outline and evaluate the history of the eugenic movement. They then describe, ethically evaluate and present legal data for ten eugenic procedures: selection of a reproductive partner, choosing the number of children, adoption, sex selection, egg and sperm selection, prenatal genetic selection, preimplantation genetic selection, human reproductive cloning, infanticide, and genetic modification.

After looking at these specific procedures, they move to a general discussion outlining both the arguments supporting and opposing eugenics in order to "evaluate whether the novel procedures being proposed should be welcomed or shunned" (p. 191). Two positive points are presented: first that "eugenic procedures may indeed facilitate the well-being of individuals and their families, and secondly that access to eugenics may assist in the functioning of a balanced and durable society" (p. 192). In the following part, they raise objections against the new eugenics. They argue that "in spite of the challenging arguments above, many of the procedures involved in the

new eugenics should perhaps be excluded from biomedical programs" (p. 211). At the center of the authors' argument is whether a person is worthy of living or not. For them, "if all persons are equal in their inherent dignity, there is no basis to select between them and it is difficult to state than any life is unworthy of life."

The authors conclude that when approaching possibilities of the new eugenics, one will have to choose between two viewpoints: "Either a person is valued for their inherent worth or they are valued for their quality of life. If they are valued for their inherent worth, then the very act of selection become meaningless since everyone is equal and choosing no longer becomes necessary" (p. 296). Two ideologies are at play here: the "worthiness of life" culture and the "quality of life" culture. They side with the former, because "A compassionate society should learn to accept all possible future children in an environment that reflects its unconditional and equal acceptance of the suffering as well as the happy child" (p. 299). Finally, they present practical recommendations on eugenics, which is the "first example of guidelines from a European ethics council on the topic of the new eugenics" (p. 301).

The book is clearly written, easy to follow and well-researched. A lay audience will easily access and understand the debate and realize what is at stake with the new eugenics. Medical procedures and technical concepts are well explained. It is a timely study that presents an alternative to the increasingly prominent voices promoting some type of new eugenics. This book provides a critical perspective on promises of better health, better lives, better children and a better society through biotechnology. By reminding us of past eugenic atrocities, we are compelled to wonder what are the atrocities that we could embrace in the future, or the ones we already have, despite our good intentions. Because good intentions alone are not enough, as the authors remind us: "motivation is a fragile guide to ethical correctness, not least because it may easily be falsified or manipulated. Defining ethical appropriateness as synonymous with good motives all but guarantees improper practices" (p. 188). We ought to be cautious with these new possibilities, as they require new responsibilities.

This book tells of the past so that the same mistakes will not happen again. It is an essential read in order to understand the historical and cultural climate in which the new eugenics is coming from, and the book puts proponents of these new technologies in their historical context. If the book has any shortcomings, it might be because it covers a lot of ground, and therefore some parts remain only introductory. Nonetheless, each argument is well presented so that we get the main points. It is a must read in our day and age, especially when biotechnology and some of its use could be a threat to all of humanity.

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Boniolo, G. and Maugeri, P. (eds.): 2014, *Etica alle frontiere della biomedicina*. Milan: Mondadori Education. 278 pages. ISBN: 978-88-6184-312-7. Price: €20.

The increase in knowledge on the fundamental biological processes, from the middle of the last century to present times, has made great contributions to the disciplines concerned with the improvement of human health on both the individual and population level. It has permitted the development of new drugs, therapies and diagnostic tools. However, this continual progress in biomedical sciences—which is the common name given to all these disciplines—manifests itself in societies permeated with diversity of values that often result in moral dilemmas and disagreements. Consequently, it has also given rise to new and pressing questions of ethical nature. This is especially evident in the field of genomics, where rapid knowledge advancements and the corresponding biotechnological developments give rise to profound ethical questions in the context of moral disagreements.

Ethics at the Frontiers of Biomedicine is a volume produced by students and coordinators of the PhD Program in *Foundations and Ethics of the Life Sciences* at the *European Institute of Oncology* in Milan. The handbook aims to provide a common ethical framework within which the ethical issues arising from the progress in biomedical sciences, and the regulatory challenges they pose, can be articulated, critically examined and evaluated, and constructively dealt with. It was devised as an aid to deliberation, serving as one of the instruments in the toolkit of the good deliberator, and it covers various themes, from embryonic stem cell research and synthetic biology to animal experimentation and experimentation on human subjects, from privacy and the right not to know to paternalism and responsibility in individual and public health settings.

Each chapter begins with plain but rigorous description of the scientific background that characterizes the issue in question; it then proposes an analysis of the conceptual tools necessary for ethical discussion; and finally illustrates the most important problems of the various proposed solutions and ways to justify or criticize them in argumentation.

Part 1 contains chapters on ethics and deliberative democracy—it is an introductory part intended to provide historical-methodological presentation to ethics, as a way to form positive or negative judgments about human behavior, and foundations of deliberative democracy, as a way to reach decisions on matters of moral disagreements. Part 2 of the book deals with various topics relating to biomedical research: moral legitimacy and private versus

public interests in embryonic stem cells research on; animal experimentation; biobanks and clinical research involving human subjects. Part 3 focuses on diagnosis and therapy, and explores ethical questions arising in the fields of regenerative medicine, genetic testing and reproductive choices, and biomedical enhancements. The forth and final part of the volume focuses on the public health sector and addresses the issues of private versus public interests through discussion of paternalism and responsibility, vaccination, life extension and eugenics.

Ethics at the Frontier of Biomedicine will equip students of various disciplines, as well as interested citizens, with the tools, conceptual and argumentative, that enable them to develop their own positions regarding the issues in question and provide well-constructed arguments based on moral grounds, keeping the ideologies and dogmas apart. The topics covered are carefully chosen to answer to the particularities of the Italian socio-cultural heritage within the wider European context that strives to produce a common European “identity”. As such, it not only represents a unique and essential empowering instrument for an Italian reader, but also provides an equally important contribution to the wider, European and international bioethical debates in the academia and public at large.

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Thiel, M.-J.: 2013, *Faites que je meure vivant! Vieillir, mourir, vivre*. Paris: Bayard. 239 pages. ISBN: 978-2227486270. Price: € 16.00.

The steady lengthening of life expectancy and the increasing numbers of elderly in the population of industrialized countries raise several issues about public health, medical ethics, social support and intergenerational justice, but it also raises the much more difficult question of how to preserve the recognition of the other and the self when aging comes.

The title of Marie-Jo Thiel’s book echoes the famous British psychoanalyst Donald W. Winnicott, who at the point of death noted in his diary, as a prayer: “Oh, God, make me die alive!...” (p. 233). This sentence, which cannot leave us indifferent, is the leitmotif of the book which is the subject of this review. Marie-Jo Thiel is a physician, a theologian, a graduated in health policy, and a professor of ethics at the University of Strasbourg. By combining these different areas of expertise, she contributes to a better understanding of aging, this “social construct full of ambivalences” (p. 7) in which “the acceptance of vulnerability remains a challenge” (p. 11).

The reflections made in this volume help also to approach with more clarity the difficulties posed by old

age, including the economic ones (“the price of human”, p. 114). Moreover, the book contributes to address these issues with serenity, recognizing the important role that elderly people have always played in society as bearers of wisdom and history (p. 106).

If “ageing is a reality that questions all of us” (chap. 1), especially at a time when society tends to exalt the young (p. 39) and does not understand well the distresses of ageing people (p. 50), the “ageing well while advancing in life” (chapter 2) is possible when it is based on solidarity between generations (p. 114) and assigns a central role to respect for personal autonomy (p. 126). Yet this recognition of the other is not automatic (p. 77).

If the greater susceptibility to Alzheimer’s disease (chapter 3), suffering (chapter 4) and disease in general (chapter 5) are often companions of the elderly, many

challenges must be overcome and more particularly that of the undeniable dignity of every human being (p. 144). Facing suffering and illness leads to address ethical questions (p. 165), and to deal with a “theology of compassion” (p. 174), which literally means a “shared passion” (p. 164). “The only genuine compassion is the one that allows those who suffer to be themselves, and moreover, to enter into a dynamic of compassion towards their own suffering condition” (p. 168).

Marie-Jo Thiel puts together three verbs (*aging, dying, living*) that show the path to be taken: “when life has been sown, living is the last phase and the one that remains” (p. 233). This is a provoking book, which challenges and reassures in equal measure its readers.

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